

Research Report

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Changes in sexual behaviour, following a diagnosis of HIV infection, in a group of South African Males.

A Research Report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Family Medicine (M Fam Med).

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Declaration

I, Ezio Baraldi, declare that this thesis is my own work. It is being submitted for the degree of Master of Family Medicine in the University of the Witwatersrand. It has not been submitted before for any degree or examination at this or any other University.

_____ (signature of candidate)

_____ day of _____ 2012

Dedication

This work is dedicated to the memory of my father

Benedino Baraldi

1931-2003

He shaped the world he lived in.

And

To the inspiration of all my HIV patients
who refuse to be shaped by the world they live in.

Publication and presentations from Research Report.

The current Research Report has not resulted in any publications or presentations as of end February 2012.

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Abstract

Background: The inexorable spread of HIV infection across all continents is attributable to many factors, including male sexual behaviour. Such behaviour is often considered recalcitrant to change.

Aim: The purpose of this study was to determine if sexual behaviour does or does not change after the diagnosis of HIV infection and to elucidate some of the psychosocial factors that may be operant in this context.

Materials and Methods: The research consisted of a structured self-administered questionnaire designed to measure ten psychosexual and socio-sexual parameters in a group of HIV positive men. The questionnaire evaluated parameters at three different time points i.e. before HIV diagnosis, one year after HIV diagnosis and the present (2002). Participants were recruited from patients attending a private HIV treatment centre, in Pretoria, South Africa.

Results: 53 participants completed the questionnaire. Descriptive statistics were used to elucidate trends. Statistically significant changes were seen in most studied domains, suggesting that beneficial change in sexual behaviour is possible after a diagnosis of HIV infection. These changes were seen, over time, in all the measured parameters, thus, change appears both possible and sustainable. This change was often detrimental to participants as it impacted negatively on some aspects of their personal and social functioning. Safer sex knowledge was weak in the studied group.

Conclusion: The data indicate that change in behaviour is possible after a diagnosis of HIV infection and occurred in the studied population. Some changes were good for public health initiatives; many were detrimental to the psychosexual functioning of participants. Public health officials and other medical practitioners should include interventions aimed at reducing the negative psychosocial impact of HIV diagnosis at every patient encounter, as these changes do not resolve by themselves over time and are detrimental to the quality of life of patients.

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Nomenclature

Abbreviations used in this publication are in common use in the field of Medicine.

Abbreviations	Full Terminology/ explanation
HIV	Human Immune Deficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
CD4	A subset of Total Lymphocytes rich in CD4 Receptors and mostly affected by the HIV virus. The measurement of this cell population is used to determine the clinical staging of patients infected with HIV.
KAP	Knowledge, Attitude and Perceptions / Practices
MSM	Men who have sex with men
MSW	Men who have sex with women
M2M	Male-to-male. A method of HIV transmission
F2M	Female-to-male. A method of HIV transmission
Statistically significant	P value less than 0.5
Highly statistically significant	P value less than 0.01

Chapter 1 Introduction

1.1 *Need for research*

One of the great debates in HIV medicine currently is the perception that men cannot, or will not, change their sexual behaviour to meet the needs for risk reduction that are the corner stone of interventions in the struggle against the spread of HIV/AIDS. Three questions follow: Is this perception correct?, Does sexual behaviour change take place after a diagnosis of HIV infection and If such a change does occur, is it sustained over time?

A multitude of different approaches and interventions have been utilised in an effort to bring about such change. Therefore, it is important to determine if such changes do occur, irrespective of the type of intervention applied .

Such a change of behaviour was accomplished in the early years of the HIV epidemic, when educational interventions were aimed primarily at gay men in the United States. Since the epidemic became a heterosexual epidemic, achieving visible behaviour change in men is thought to be impossible to achieve at a meaningful level.

Campaigns to empower women to take the lead in safer sex interventions were undertaken. After a few years, it was felt that for most women, it was not possible to take the lead in matters sexual while having to live in patriarchal societies. The campaigns have, in some instances, led to a power struggle in relationships and communities; consequently, the impetus of these campaigns has been diminished.

Subsequent campaigns launched by WHO and UNAIDS, have focused on including the male partner again in the prevention efforts and making him co-responsible for prevention efforts and to stimulate the caring and nurturing aspects of men.

While the global statistics fail to show a decline in the incidence of HIV in most parts of the world, more localised studies have shown changes of behaviour in certain studied populations. Sexual behavioural patterns once established are very difficult to change and are dependent on a number of factors, many of which are independent of gender.

The study was undertaken to evaluate if a change of behaviour had indeed occurred in a group of HIV positive South African men following a diagnosis of HIV infection. The men had all undergone treatment and ongoing counselling, over a period of time, in a specialised HIV treatment centre.

1.2 *Historical Perspective*

Since the emergence of the HIV epidemic in the middle 80's, men have been seen as the drivers of the epidemic. Initially the disease was confined (in the US) to the gay population and thus men were the logical targets for intervention. A great number of intervention programs were initiated, all with the aim of either reducing exposure to the virus by means of the adoption of safer sex procedures, or by reducing the number of sexual contacts.

Already in 1988, Siegel et al¹ reported the effects of these campaigns. At the time, Siegel reported that while there was a measurable reduction in sexual partners in his New York cohort, there was not a commensurate reduction in risky sexual practices, despite high levels of knowledge of risk reduction procedures.

In 1989 Johnson and Gill² similarly reported behaviour changes in gay and bisexual men in England and Wales, with the same results. Some changes in behaviour had occurred but many men were still engaging in high-risk sexual behaviour despite a reduction in sexual partners.

By 1990, reports from Ekstrand et al³ in San Francisco and Hakansson⁴ in Sweden indicated that the only change in risk taking behaviour, was a

reduction in sexual partners, in their respective cohorts of gay men. Sexual behaviour change was therefore possible in gay men. The challenge was to sustain this behaviour change over time. This was confirmed by Stall et al⁵ who in 1990 published a review of their five-year prospective data on the changes in sexual practices in a high HIV incidence area (San Francisco).

In 1990, Kelly et al⁶ studied the psychological factors that had an effect on the initiation and maintenance of safer sex behaviour in a group of gay men. In their work, risky sexual behaviour was positively associated with: “Perceived peer norms” concerning the (1) acceptability of safer sex practices; (2) AIDS health locus of control scores (3) risk behaviour knowledge (4) age and (5) accuracy of personal risk estimation, but not personal HIV serostatus knowledge.

These are some of the key determinants of a person’s ability to initiate sexual behaviour change. In a South African heterosexual setting, others could be added, in particular cultural belief systems and practices, as well as, partner acceptability of safer sex practices.

Since the 1990’s, the spread of HIV infection has been a predominantly heterosexual phenomenon worldwide. The entry of heterosexual men in the HIV risk pool required that educational activities aimed at risk reduction had to be initiated in this at-risk group. Prior experience with the design and implementation of interventions aimed at gay men was used to design similar interventions for heterosexual males. The addition of a female partner to sexual activities substantially broadened and complicated the discourse. The female partner often brought to the debate, a different perspective of sexuality, which required a different approach to the educational interventions.

By the mid 90’s there was a clear understanding that safer sex messages had to be tailored to the specific populations for which they were intended. Various articles were written to address this need^{7,8} and for the first time the needs of women were factored into these prevention strategies.

In 1992, Holland et al⁹ explored safer sex options in a group of women from London and Manchester in the UK, within a context of feminist theory and methodology. They explored the themes of "risk and trust" and "power and empowerment" The lack of women empowerment worldwide became a key element in HIV prevention strategies. Much work was done to empower women to take a more active role in safer sex decisions. ^{10, 11, 12, 9,13,14,15}

The empowerment of women to make sexual decisions is difficult in male dominated societies. In many communities, women are physically and financially vulnerable and place themselves at considerable risk of retribution when challenging the authority of their male partners in matters of sex. ^{15,16,17,}

This empowerment of women is often seen as disempowerment by men leading to a potential shift in the power balance in relationships with severe consequences. Any destabilizing influence can lead to power struggles within relationships. In a male dominated society, women are unlikely to emerge better off than before, from such conflicts. Fortunately in the past few years, this power debate has subsided, reducing the potential level of conflict. HIV interventions are now no longer at the forefront of the struggle for gender equality, although this remains a factor. Interventions have now been focused on factors that can be modified, within the context of individual communities and their belief systems.

The focus is now on all aspects that can reasonably be modified within the cultural context and where possible, integrating the belief systems of the target communities in the prevention efforts. ^{18,19}

A realisation is beginning to emerge that in order to change sexual behaviour one needs to change sexual beliefs, as these are primary determinants of behaviour in later life ²⁰

Chapter 2 Literature review

The literature review for this study was conducted by means of online databases searches. Databases searched were Medline and Pubmed.

Mendeley was used as the citation manager. Search terms included HIV, AIDS, Men, behaviour change, safe sex, abstinence, monogamy, condoms, attitudes, self-esteem, barrier contraception, religion, microbicides, seroconversion, serosorting, circumcision, polygamy, HIV status, depression and revenge, concatenated with HIV status and behaviour change, amongst others.

2.1 Introduction

From the inception of the epidemic, once it became clear that the prime causative agent was a sexually transmitted virus, ways have been sought to limit the spread of the virus between sexual partners. These interventions focused on two primary interventions.

- a) Physical and chemical barriers to the spread of the virus and
- b) Behavioural interventions aimed at changing people's behaviour in order to minimize spread.

2.2 Physical and Chemical Barriers.

Physical barriers to the spread of HIV were the first logical way of reducing the spread of the virus. The wide spread use of condoms, having fallen from favour in the 1960's due to the introduction of the contraceptive pill, was revived. The revival was not very successful from the outset and resistance to the use of condoms was soon documented. In 1987 Wigersma ²¹ commented that although the thickest condoms should be used for safety, the gay population he studied did not take kindly to them.

On a cultural basis many barriers to condom usage were identified. Potts and Short, in 1989²² looked at global condom usage and found that it was low in

most third world countries. they found the highest usage in Japan, Sweden, Finland, Denmark, Singapore, Trinidad and Tobago and predicted that usage in poor third world countries would be driven by cost. He suggested massive funding to increase distribution and availability.

A more recent development is the research into chemical barriers to prevent the spread of HIV. In the early years of the epidemic, spermicides, and in particular nonoxil-9 were mooted as being effective.²³ Very soon, research emerged showing the in vitro consistent ability of the compound to inactivate HIV virions. This was quickly followed by reports of local toxicity and ulceration of vaginal and rectal epithelium with repeated use of the compound²⁴. This ulceration is now believed to increase susceptibility to HIV and other STI's.²⁵ The use of nonoxil-9 and other similar spermicidal compounds is currently strongly discouraged.

Research on chemical barriers that can prevent the entry of HIV, has continued, and has focused on microbicides. Microbicides, as opposed to spermicides, are chemical entities designed to inactivate HIV without necessarily killing sperm. While some significant progress is being made in the field, there is no viable entity that can be used on a wide scale.^{26,26,27,28} Progress in this field of research has been slow but steady and the compound Tenofovir seems to be yielding encouraging results in its latest formulation as a microbicide. The CAPRISA study, which tested a 1% tenofovir gel showed moderate effectiveness in high adherents (usage more than 80% of the time) with a 54% reduction in incidence of new infections.²⁹

2.3 Behavioural changes

Behavioural changes to bring about a reduction in transmission of HIV virus, have, from the earliest days of the epidemic, been promoted as a way of combating the epidemic. Behavioural change is seen as being cost-effective, immediately applicable (as opposed to waiting many years for research to produce a viable compound), and acceptable to society.

In the context of the HIV, epidemic interventions have focused on abstinence, monogamy and fidelity as well as the consistent application and usage of safer sex practices, which go beyond the mere use of condoms. This has led to the so-called ABC³⁰ program- Abstinence, Be faithful, Condoms being an approach much favoured by the funding commitments of the Bush administration and fully supported by fundamentalist religious groupings.

The required behavioural changes can be divided into:

1. Changes in sexual activities and
2. Changes in partnering.

Measurement of the effectiveness of these interventions has focused on self-reported evaluations of Knowledge, Attitude, and Perceptions (the KAP surveys). Real evaluation of the changes in sexual practices on an individual level is virtually impossible to do and such changes must be gleaned indirectly from epidemiological data

2.4 Changes in partnering

Required changes in partnering normally involve: (1) abstinence from sexual contact until after a long-term relationship has been established;(2) reduction in the number of sexual partners while searching for a relationship partner, and (3) maintaining monogamous relationships once “permanent or long term” partnering has occurred.

Abstinence has been widely advocated especially through religious groupings. Results worldwide have been measured at different time points and geographical locations. Results are inconsistent and unpredictable^{31,32} and are dependent on a number of factors including double standards in sexual practices. As sexual beliefs and practices are culturally determined and subject to change³³ it follows that global results will be variable.

Monogamy and the reduction in casual sexual partners have also been widely advocated as intervention strategies. A review of meta data in 2008³⁴ found that although such interventions were effective to some degree, the gain was

small and in general not sustained over time. The outcome of these interventions was susceptible to a variety of factors such as ethnicity, locality, culture etc.

A recent change in behaviour, predicated on a rejection of the ABC intervention, has become apparent in the gay community. As HIV antibody testing has become more prevalent in this community and many more people know their status, the phenomenon of serosorting has emerged.

Serosorting involves a stratification of risk taking behaviour based on the partners' known HIV status. In its basic form, serosorting involves using safer sex procedures only with partners of discordant serostatus from themselves. Thus, well-informed patients are determining for themselves, the amount of risk they are willing to take in any given sexual encounter³⁵. In its advanced form, serosorting introduces HIV treatment status and prior treatment modalities into the equation, thus leading to a large number of added permutations. This intervention is risky and offers limited protection^{36,37} but it is an intervention that takes cognizance of the polygamous nature of men, and offers the possibility of sustained risk reduction as opposed to the ABC approach where the behaviour change fades quickly after an intervention. A variant of serosorting is commonly practised by polygamous African men in Africa, where condoms are used with casual partners but not with their spouses in the belief that the wife is monogamous.

2.5 Changes in Sexual Activities

Advocated changes in sexual activity, normally referred to as safe sex (or more appropriately safer sex), form the cornerstone of the C section of the ABC intervention and focus on the consistent use of Condoms, which is only a small component of the safer sex intervention. In an article³⁸ which appeared in "AIDS Action" (no authors listed), the author, writing approximately 10 years after the emergence of the epidemic, acknowledges that changes in behaviour are difficult to achieve and goes to some lengths in explaining what safer sex actually is. He states: "Some options for practising safer sex include

non-penetrative sex or penetrative sex with a condom. Oral sex is less risky than unprotected penetrative vaginal or anal sex, but this should be avoided if there are sores on the genitals, mouth, or lips. When a condom is used with oral sex, or a piece of latex is placed over a woman's genitals, risk is further reduced. Safer sex is an activity that prevents semen, vaginal fluids, and blood from entering another person's body or coming into contact with broken skin. Safe sex options should be presented in a positive manner which encourages people to explore what methods they would be comfortable to use with their partners.”

The operative concept here is that safer sex is any activity that prevents sexual fluids and blood from entering another person's body or coming into contact with broken skin. To a very large extent this implies the application of techniques to reduce cross-contamination – much as a one would use in outpatient surgical procedures (not sterile but surgically clean). This level of detail and instruction is hardly ever given to patients during safer sex interventions, which concentrate, in the main, on using a condom for penetrative activities. After a safer sex counselling session the patient therefore, is, only empowered with a small piece of the puzzle.

As the thrust of these interventions is to limit the amount of unprotected penetrative events, evaluations of these interventions have focused on tabulating a reduction in these activities mostly from self-reported sources
39,40,41

The latest intervention for the reduction of the spread of HIV (at least in Africa) is mass circumcision of the male population. In 1994 Hunter published his findings of a study of transmission rates for STI in Kenya ⁴² and found that women who had circumcised partners were three-fold less likely to be HIV positive when compared to women whose partners were not circumcised. Two years later, De Cock mentions circumcision as a potential intervention to stem the spread of HIV. ⁴³ Researches proceeded to do large-scale studies to

verify these findings. By 2008, three^{44–46} large-scale randomized studies, one conducted in Orange farm in South Africa, showed a reduction in the spread of HIV from women to circumcised men resulting in a delay in HIV acquisition of 3.5 years. This would lead to a 25% reduction in HIV infections based on epidemiological data.⁴⁷ These findings form the basis on which the United Nations Joint Programme on HIV/AIDS (UNAIDS) recommends massive up scaling of circumcision services throughout sub-Saharan Africa.⁴⁸

This intervention is greatly contested and a number of authors have argued against it for a variety of reasons, from the basis of weak and inappropriate evidence, through public health concerns that this would undermine already established interventions and lead to an increase in new infections, to concerns about human rights violations.⁴⁹

The debate rages on.

2.6 Barriers to Change

Barriers to change in sexual practices can be divided into three main categories: personal, cultural and relationship. While these are interrelated and it is worth exploring them individually, such an exercise is beyond the scope of this document.

2.7 Sexual Behaviour changes

Given the number of interventions that have been tried⁵⁰, and the multiple barriers to change that have been described in the literature, the final question needs to be answered: Is a positive change in sexual behaviour possible and sustainable after a diagnosis of HIV infection? In other words, what is the collective effect on behaviour of all these interventions?

In 2006 Bunnell et al ⁵¹ explored this question from May 2003 to December 2004 in a prospective group of patients (male and female) initiating antiretroviral treatment in Uganda. Participants received standard HIV counselling on risk reduction methods and PCT. Counselling was provided to partners as well. Results of this intervention showed that at six months after initiation of ARV treatment, risky sexual behaviour had declined by 70%. It remains to be determined if this change is sustained over longer periods of time, but for the six months after the intervention, change was possible and was documented.

Similarly Venkatesh et al ⁵² evaluated the reduction in risky sexual behaviour in a group of Southern African women after diagnosis of seroconversion, which they reported in 2011. Evaluation was performed by three monthly questionnaires in the context of a clinical trial. They reported reduction in risky sexual behaviour [reduction in partners, reduction in sexual activity, and reduction in sexual activity, such as anal sex]. They reported that such reduction in sexual behaviour was modest and that more interventions are required.

In 2002 Colfax et al ⁵³ reported on changes in sexual behaviour in a group of Men who have sex with Men (MSM). The study was prospective and evaluated risky behaviour before, immediately after and 12 months after seroconversion. They concluded that a substantial potential exists for secondary HIV transmission during and for one year after HIV seroconversion despite the fact that receipt of an HIV positive test result was associated with a significant reduction in risky sexual behaviour.

A study conducted in northern Italy of the five HIV treatment centres in 2006 by Camoni ⁵⁴ aimed to discover changes in risky sexual behaviour in HIV-positive patients over the age of 18 enrolled in treatment programs. The majority of participants were male (65% of 497 participants). They reported that although condom use increased after a diagnosis of HIV, as did the number of stable partners, unsafe sexual practices continued and they

recommended specific interventions aimed at this population. Other literature: confirms these small-scale changes^{.55,56,57,58,59,60,61,62,63}

Recent literature, therefore, seems to confirm earlier publications that although changes in sexual behaviour after a diagnosis of HIV infection do occur, the degree to which this happens and the sustainability over time of these changes, is not in keeping with the requirements and expectations of public health interventions. These findings appear to be consistent across population groups and geographic locations.

The current study was undertaken to determine if similar trends were operant in the study population.

Chapter 3 Aims and Objectives

3.1 Aim of study

The aim of the study was to determine if there is a change in male sexual behaviour after the diagnosis of HIV infection.

3.2 Objectives

Objective 1

To define and describe the demographic characteristics of the study participants including age, ethnic group etc

Objective 2

To describe psychosocial factors and perceptions associated with sexual functioning in a group of HIV positive men including; adjustment time; mode of transmission; self-esteem and identity; drive and enjoyment; anger and revenge; accessibility to sex; knowledge of safer sex; negotiation skills and social functioning at time points before HIV diagnosis, one year after HIV diagnosis and the present (i.e. 2002)

Objective 3

To look for relationships and, or, associations between the above factors.

Chapter 4 Design and Methodology

The research project is a descriptive cross sectional study to describe some psychosocial factors involved in the sexual functioning of a group of HIV positive men, by means of a structured anonymous questionnaire. A self-reported, cross sectional, retrospective (at two different time points in the past, and one time point in the present), and self-administered questionnaire methodology was adopted.

4.1 Site of study

The research was conducted at Embassy Drive Medical Centre, a private HIV treatment and research centre situated in a suburb of Pretoria. The centre applies internationally accepted treatment methodologies based on first world best practice principles and is owned and operated by the researcher.

4.2 Study Population.

The study population consisted of known HIV positive patients attending Embassy Drive Medical Centre in Pretoria. The centre serves mainly middle and upper class employed patients who are part of some form of medical insurance programme. All potential subjects were recruited from existing patients at the centre and no recruitment from outside sources took place.

4.2.1 Socio Political Context

The study was conducted during the height of the Mbeki AIDS denialist era in South Africa. At the time messages in the media and from influential politicians conflicted strongly with medical messages leading to confusion in many HIV positive individuals. These pseudo science messages were actively countered by Embassy Drive Medical Centre at the time.

Patients participating in the study were well informed and most had been on ARV treatment for some time (either privately funded or as participants in clinical trials) and were well aware of the benefits of treatment. It is therefore

possible but unlikely, that Mbeki AIDS denialism had an effect on the Knowledge Attitudes and Perceptions of the study participants.

4.3 *Sampling*

4.3.1 Sample size

A desired recruitment target of 100 evaluable patients was set as the expected maximum number of potential participants from the population of males that could realistically be enrolled from the study site. The study was not statistically powered to show differences between subgroups in this population. Regretfully the intended sample size was not reached and is described in full in section 4.13. Statistical Limitations.

4.3.2 Sampling time

Data was collected from March 2002 to December 2002.

4.4 *Sample Population.*

The sample population consisted of all known HIV positive males attending Embassy Drive Medical Centre. The majority of patients were in the 30 to 40 age group with some outliers. The majority of respondents were on Anti Retroviral Treatment at the time of participating in the study. Although such detail was not collected by the questionnaire, it is known (as these were existing patients) that most patients were employed and were subjectively judged by the investigator to possess linguistic skills sufficient for comprehending the study. This was further determined during the informed consent procedure once patients accepted to participate in the study.

Some of the patients had been participants in other pharmacological studies and were well versed with trial related procedures and the concepts of informed consent and confidentiality.

4.5 Inclusion criteria:

1. Serostatus: Confirmed HIV positivity;
2. Gender: Male only;
3. Age: 18 years of age or older.

4.6 Exclusion Criteria

1. Patients unwilling or unable to give consent;
2. Patients who have already completed the study;
3. Patients who fail to meet inclusion criteria.

4.7 Measuring Instrument

Participants were asked to complete a self-administered questionnaire which included one open ended question, a number of yes/no questions and a large number of questions where participants were asked to grade their responses on a supplied scale as well as to score such responses on a time line.

The time-line points were defined as

1) Before HIV diagnosis;

Participants were asked to answer questions relating to their behaviour and KAP before their HIV diagnosis, whenever that was in the past.

2) One year after diagnosis;

Participants were required to subjectively evaluate their behaviour and KAP one year after their HIV diagnosis.

3) Present i.e. at the time of taking the questionnaire (2002).

Participants were asked to evaluate the same parameters in the Present i.e. 2002.

Section two of the questionnaire consisted of agree/disagree answers designed to Test behaviour and KAP in the present, i.e. at the time of taking the questionnaire.

4.7.1 Questionnaire development.

The questionnaire was designed by the investigator as validated instruments that measured the parameters that the researched wished to investigate, were not found.

4.7.1.1 Purpose.

Based on the Aims and objectives of the study and the population being studied, and especially due to the intimate nature of field of study, the researcher decided that the correct instrument to use would be an anonymous, self-administered questionnaire as opposed to a structured interview method (see social acceptability bias)

4.7.1.2 Conceptualisation.

The researcher decided to subdivide the changes to be investigated in KAP and behaviour over time, into 10 different domains (Table 1) that might inform the observed changes if any. The changes were to be measured over three different time points. This data pooling was part of the protocol and was approved by the Post Grad committee at Wits .

4.7.1.3 Question construction.

After deciding on which domains were to be investigated, questions were constructed which either directly or indirectly informed the domain in question. For each domain a large number of potential questions were generated. These questions were then scrambled and placed in a matrix against the domains. The investigator then marked which questions informed, directly or indirectly, which domain. The assistance of a clinical psychology colleague was requested to do the same exercise. The resulting tables were then merged.

Questions which informed more than one domain were preferentially retained (for the sake of questionnaire brevity and to avoid respondent's fatigue) for inclusion in the final questionnaire. Some duplicate questions were retained for internal congruency and some were reworded.

4.7.1.4 Measurement scales.

The questions were divided into two sections. Section one was constructed to measure changes over three different time points.(1) Before HIV diagnosis, (2) One year after HIV diagnosis and (3) Now (the present i.e.2002)). For each of these time points a four point scale was used and respondents were asked to rank their responses as :1=Almost never , 2= Sometimes, 3=Most of the time and 4= Almost always.

The second part of the questionnaire was constructed as a simple KAP questionnaire to collect data in the present (Now, i.e. at the time of completing the questionnaire in 2002). A three-point scale was used to grade responses (1) Agree. (2) Don't agree and (3) Don't know: In order to minimise the Don't know option, this choice was disallowed in most questions except where it made sense as a legitimate answer , as in question 53."Sex without a condom is a criminal offence", where the "don't 'know" answer would constitute a valid answer.

4.7.1.5 Validity.

The questionnaire was tested amongst colleagues and lay people to determine the acceptability of the questionnaire Particular attention was paid to discovering incongruencies in the questionnaire and the emotional acceptability of the questions, as intimate issues were probed by the questionnaire.

Readability was determined based on the opinions of this group and not on a particular readability index. Concepts such as; steady, regular. occasional and anonymous sexual partners, used in the questionnaire, were well understood in the test group and were deemed to be equally understandable by the envisaged test population.

As a result of this testing some of the wording was changed and simplified in order to increase understandability and readability. Some questions were

removed and new ones added to achieve a better fit with the required domains.

4.7.1.6 Reliability.

The reliability of the questionnaire was established by means of a small pilot study. After obtaining ethics approval, well-known patients in the practice were asked to volunteer to test the instrument. Five patients (who met inclusion and exclusion criteria) completed the questionnaire. The responses were manually evaluated .

Their perception of the questionnaire and particularly their emotional responses to the questionnaire were evaluated by means of an interview with the investigator. As a result of the findings in this pilot study, it was decided that the emotional impact on participants induced by completing the questionnaire, could be significant. It was decided to offer two free counselling sessions to participants who felt a need for it. Results from this pilot study were not used in the study itself.

Questions were designed to inform the following domains:

Table 1: Domains

	Domains	Questions
1	Demographics	Questions in demographic section
2	Adjustment time	Date of first diagnosis to present (2002)
3	Mode of transmission	In demographics section
4	Self-esteem and identity	1,22,24,26,29,30,34,45,46,
5	Issues of drive and enjoyment	1,2,3,12,15,20,21,31,32,44,
6	Issues of anger and revenge	8,14,33,35,40,41,47,53,54,
7	Accessibility to sex	5,6,7,11,16,
8	Knowledge of Safer sex	23,39,42,43,49,52,53,55
9	Negotiation skills	4,10,13,27,37,50,
10	Social functioning	22,24,26,29,30,36,39,45,46,51,54,

4.7.2 Social Acceptability Bias

As this questionnaire was thought to be particularly susceptible to the effects of Social Acceptability Bias⁶⁴, the following measures were used to reduce the impact: Voluntary participation, anonymous data collections, privacy in form completion and anonymous form submission.

4.8 Pilot study.

See 4.7.1.6 Reliability.

4.9 *Data collection and study specific procedures.*

The protocol required that 1 in 3 eligible patients who presented at the centre (i.e. who met inclusion and exclusion criteria) be entered in the study. Primary eligibility was determined by the nurse who made the appointments at the centre. (Note: These were known patients in an HIV treatment Centre, where patient confidentiality is guaranteed. Each staff member is contractually bound

to the Doctor to maintain the same standards of confidentiality that are required of the practitioner. This standard of confidentiality is applied to all medical information and is communicated to patients when they join the treatment centre.)

The nurse placed a green blank record card in the file of each 1st and second successive patient and a white blank record card in the file of every third successive eligible patient. The nurse did not discuss the study or any of its related procedures to the participants.

This procedure was deemed essential as it allowed the nurse to adjust consultation time and appointments to include the extra time required by the doctor to complete the informed consent procedures.

After completing the normal consultation process (for which the patient had made an appointment), the researcher offered the study to the potential participant.

The informed consent document was explained to the patient by the investigator and potential participants were given the opportunity to ask questions about the study. Patients were particularly alerted to the possibility that completing the questionnaire may cause them to think about issues, which they may not have previously considered, and that this might prove distressing. Should this eventuality arise, two free counselling sessions were offered to the participants, either with the investigator, or with the centre psychologist, depending on the nature of the problem.

Patients who refused to participate (for whatever reason) were assured that this decision would not have any impact on their future medical care. Refusal reasons were not collected.

Once the patient had indicated his willingness to participate, two copies of the informed consent document were signed by the participant and the researcher. The attending physician then reminded the patient of what his

latest CD4 count was (as this data was collected in the questionnaire). The participant was then handed one signed copy of the informed consent document for his own records (*informed consent document see appendix 2*), as well as the questionnaire to be completed. The participant was then shown to a private room where he could complete the questionnaire.

On completion of the questionnaire, the patient was instructed to place it in the appropriate box, which was located in the same room. The box was designed as a closed entity with a slot for introduction of the completed questionnaire. This impeded retrieval of other documents already in the box.

A notice placed on the results box reminded participants of their free counselling consultation should they need one. No Participant made use of the offer.

Although participation in the study was entirely anonymous, once a patient had indicated his willingness or refusal to take part in the project, his file was marked (by leaving the white blank record card in the file) by the attending physician to indicate that the study had already been offered to this person. The file was not marked to indicate if the patient completed the questionnaire or not. This was to avoid offering the study to the same patient twice and thus maintain the 1:3.ratio as required by the protocol.

An evaluable patient was defined as one who had agreed to participate in the study and had answered at least one question in the questionnaire.

4.10. Bias and Validity

The possibility exists that patients may have answered the questionnaire by selecting the answers that they thought the researcher wanted to hear.(social acceptability bias see section 4.7.1) This was foreseen and internal control questions were included to minimise this effect.

Researcher bias originates from preconceived ideas based on previous experience. To minimise this effect, the questionnaire was subjected to evaluation by outside parties in order to ensure that the questions covered all required aspects. Similarly, the inferences from the observed trends were also subjected to external review for validity in deductions.

4.11. Ethical considerations.

The Human Research Ethics Committee (HREC number: M01-05-30) was supplied with all required material, including the informed consent/ information document. The study was commenced only after appropriate approval had been obtained and no study related procedures were initiated prior to that event.

The study was conducted in accordance with the Declaration of Helsinki as amended in October 2000.

4.12 Statistical Methods

The study was conducted during 2002 (March to December) at Embassy Drive Medical Centre. A total of 69 patients were approached to participate in the study. Sixteen patients refused. The refusal rate was 23.2%. A total of 53 participants were finally enrolled in the study

The study design required a selection of 1:3.patients. In practice, this resulted in a situation where only one patient out of three that attended the practice could be offered participation in the study. As all files were marked once a patient had attended, the study could not be offered to them again. The study was not offered to patients a second time.

This patient selection methodology severely limited the number of patients that could be enrolled in the study within the preset enrolment period (March to December 2002). The end of 2002 cut off date for recruitment was

necessary in order to maintain the PRESENT category within the calendar year of 2002. Without this limitation, the PRESENT category would have spread over two different years, thus increasing adjustment time for the later participants and potentially skewing the data

4.13 Statistical limitation of the results

The study was not powered to show differences between subgroups, but was designed to show trends over time. The study generated many possible statistical comparisons, not all of which are explored in this document. All statistical data is shown, however, in the data section of the document. Where statistical differences between groups, or time points, became obvious, these were explored, and are included in this document. The number of evaluable patients was 53.

The raw data contains missing values for some questions, omitted by respondents. This missing data was treated as unknown data. An intent-to-treat approach was not used, and unknown data was removed from the denominator.

The questionnaire produced a large number of results. In section 2 of the questionnaire, participants were requested to note their responses on a four-point scale [almost never, sometimes, most times, almost always] over three different time points [before diagnosis of HIV, 1 year after a diagnosis of HIV, and now in 2002]. For the sake of statistical evaluation, responses in the almost never and sometimes categories, were combined into a new category called *less often*, while the categories most times and almost always were combined into a new category called *more often*.

Section 3 of the questionnaire tested attitudes and perceptions at the time of taking the questionnaire in 2002. Results are reported by domain and by question. Statistical significance was calculated using the MacNemar test, and is reported. Statistical significance is indicated by a P value less than 0, 05 i.e.

a less than 5% chance of a Type 1 error (rejecting the null hypothesis when it is true) .P values <0.001 are considered to be extremely significant.

Statistical evaluation was performed by: SAS Release 9.2, running under Microsoft Windows for a personal computer. Frequency counts, percentages and MacNemar tests were performed using PROC FREQ.

Chapter 5 Results

5.1 *Demographics*

5.1.1. Ethnicity

The majority of participants were either of Caucasian descent 17 (32%), or of African descent 32 (60.37%). One (2%) participant was of Asian descent and one (2%) of mixed ethnic descent. Two participants (4%) did not disclose their ethnic descent.

5.1.2 Age

The average age of participants was 38 years (median 37 years) with a range of 25 to 60 years.

5.1.3 Year of Testing

The majority of respondents had been tested for HIV infection in 1997. However the average time for Caucasian patients was in 1994, while the average time for African patients was 1998 (the date range is from 1985 to 2001).

5.1.4 CD4 Values (cells/ml)

The average latest CD4 value for Caucasians was 344, while the average latest CD4 for value for Africans was 410. The average CD4 value for the group was 393 with a median of 313 (Range of 2-1359)

5.1.5 Method of HIV Transmission

This question was answered by 40 (75.5%) respondents. The majority signified a sexual mode of transmission 38(71.7%), while two (3.8%) respondents. indicated a direct blood-to-blood transmission route. Thirteen

(24.5%) respondents failed to answer this question. Of the 40 patients who answered this question 19 (47.5%) indicated a male-to-male (M2M) route of infection while 19 (47.5%) indicated a female-to-male (F2M) route of infection.

5.1.6 Partner profile

Participants were asked to indicate what their source of HIV infection was. Ten (18.9%) respondents indicated that they had acquired their infection from their usual/regular partners, 13 (24.5%) from casual partners, three (5.7%) from sex workers and 23 (43.40%) indicated that they did not know where their infection came from. Four (7.5 %) respondents failed to answer the question.

5.1.7 Reason for testing

Participants were asked to disclose their reason for taking an HIV test. Of the respondents, 20 (37.7%) reported that they wanted to know their status and an equal number, 18 (34.0%) reported that they were sick at the time of testing. Only three (5.7%) respondents underwent an HIV test as a result of their partner being diagnosed with HIV. A proportion of respondents, 12 (22.6 %), were tested for insurance purposes.

There was no difference in the reason for testing between ethnicity groups.

5.1.8 Place of testing

Participants were asked to indicate the place where they were tested. The majority of participants were tested by a private doctor 41 (77.4%), while a smaller number, seven (13.2%) reported being tested directly by a laboratory; three (5.7%) were tested at a government hospital and two (3.8%) reported being tested at a government clinic.

5.1.9 Counselling

Participants were requested to indicate if they had received any counselling as part of their testing process. Of the respondents, 28 (52.8%) reported receiving no counselling at all, 11 (20.8%) reported receiving both pre and post counselling. and ten (18.9%) respondents reported receiving post- test counselling only.

5.2 Results by Domain

This section of the questionnaire describes the sexual functioning of patients before a diagnosis of HIV infection, within the first year of HIV infection and their functioning in 2002. (See *appendix One for full set of questions*).

Questions in the questionnaire which most directly tested changes in sexual activity before and after a diagnosis of HIV infection were : 5,6,7,8,10,11,12,14,16,18,20,21. These questions elucidated sexual activities that should either be actively embraced (Table 5.1) or avoided (Table 5.2) in order to decrease risky sexual behaviour. Collective results for these two factors, are therefore, presented in two separate tables.

Table 5.1 : Changes in Sexual Behaviour

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
All responses: Questions 8, 10, 11, 14, 20 and 21			
Less often	183 (70.4)	116 (45.7)	100 (38.5)
More often	77 (29.6)	138 (54.3)	160 (61.5)
Total	260 (100)	254 (100)	260 (100)
Non-responders	58	64	58
P value relative to "Before"		< 0.001*	< 0.001*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Q8: *I use condoms with my steady partner*

Q10: *I am comfortable suggesting a condom before sex*

Q11: *How frequently do you have safer sex*

Q14: *I use condoms with my casual partner*

Q20: *I prefer masturbation*

Q21: *I prefer not to have sex*

Table 5.1 shows a decrease over time in the less often category and an increase in the more often category. This is a statistically extremely significant at time point one year after HIV diagnosis as well as the present in 2002. Therefore, the number of participants who had practiced risky sexual behaviours before a diagnosis of HIV decreased and the number of participants who already practised safer sex behaviours prior to a diagnosis of HIV infection, increased over time. This change is extremely statistically significant at both time points.

Table 5.2: Decrease in risky sexual activities

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
All responses: Questions 5, 6, 7, 12, 16 and 18			
Less often	166 (64.1)	200 (78.1)	215 (82.1)
More often	93 (35.9)	56 (21.9)	47 (17.9)
Total	259 (100)	256 (100)	262 (100)
Non-responders	59	62	56
P value relative to "Before"		< 0.001*	< 0.001*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Q5: *How frequently do you have sex with steady partner?*

Q6: *How frequently do you have sex with casual partner?*

Q7: *How frequently do you have sex with anonymous partner?*

Q12: *I use alcohol before sex*

Q16: *I prefer sex with casual partners*

Q18: *I prefer oral sex*

Table 5.2 shows an increase in the less often category and a decrease in the more often category from baseline. Therefore, participants became more likely to engage in safer sex and less likely to engage in risky sexual activities one year after a diagnosis of HIV as well as at the time of taking the questionnaire in 2002, irrespective of whether they had engaged more often or less often in these activities before the diagnosis of HIV infection. These changes in sexual behaviour were statistically extremely significant at both time points.

Table 5.3 : Domain 4: Self-esteem and Identity.

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>Q1: Do you think you are sexually attractive</i>			
Less often	17 (37.8)	21 (46.7)	28 (62.2)
More often	28 (62.2)	24 (53.3)	17 (37.8)
Total	45 (100)	45 (100)	45 (100)
Non-responders	8	8	8
P value relative to "Before"		0.206	< 0.001*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Table 5.3 shows a change in self-perception over the studied time period. The number of participants who had a low perception of their own attractiveness increased over time and the number of participants who had a good perception of their own attractiveness decreased over time. These downward trends reached extreme statistical significance at the 2002 time point.

Table 5.4 : Domain 4 : Self-esteem and Identity – KAP questions

Number (%) of participants				Non-responders
Agree	Disagree	Do not know	Total	
Q22: If I don't have children my family will repudiate me				
10 (20.0)	34 (68.0)	6 (12.0)	50 (100)	3
Q24: I am not the man I used to be				
27 (51.9)	21 (40.4)	4 (7.7)	52 (100)	1
Q26: HIV has made me loose my status in my community				
10 (19.6)	37 (72.6)	4 (7.8)	51 (100)	2
Q29: If I use a condom, people will gossip				
5 (9.8)	44 (86.3)	2 (3.9)	51 (100)	2
Q30: If I use a condom there will be a fight with my partner				
1 (1.9)	49 (94.2)	2 (3.9)	52 (100)	1
Q34: Real men don't use condoms				
7 (13.7)	42 (82.4)	2 (3.9)	51 (100)	2
Q45: It is not in my culture to use a condom				
6 (12.0)	43 (86.0)	1 (2.0)	50 (100)	3
Q46: I am often sad				
26 (50.0)	24 (46.2)	2 (3.8)	52 (100)	1
All responses (n=409)				
All PH answers: 294 (71.9%)				

Table 5.4 shows collective results from the KAP questions as of the time of completing the questionnaire in 2002. Collective answers show that the majority of respondents for these questions (71.9%) responded with PH answers (in bold in the table) and showed a good self-esteem. However,

individual answers to questions 24 (“I am not the man I used to be”).and 46 (“I am often sad”) are indicative of a decline in self-esteem. The majority of respondents to question 46 agreed that they were often sad.

Note: PH answers were Investigator defined as those answers given by participants that comply with social norms or which are conducive to the attainment of public health goals.

Table 5.5: Domain 5 : Drive and enjoyment.

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>Q1: Do you think you are sexually attractive</i>			
Less often	17 (37.8)	21 (46.7)	28 (62.2)
More often	28 (62.2)	24 (53.3)	17 (37.8)
Total	45 (100)	45 (100)	45 (100)
Non-responders	8	8	8
<i>Q2: Are you satisfied with your sex life</i>			
Less often	13 (28.3)	22 (47.8)	28 (60.9)
More often	33 (71.7)	24 (52.2)	18 (39.1)
Total	46 (100)	46 (100)	46 (100)
Non-responders	7	7	7
<i>Q3: Do you have a high sex drive</i>			
Less often	10 (21.7)	23 (50.0)	24 (51.1)
More often	36 (78.3)	23 (50.0)	23 (48.9)
Total	46 (100)	46 (100)	47 (100)
Non-responders	7	7	6
<i>Q12: I use alcohol before sex</i>			
Less often	31 (67.4)	38 (84.4)	43 (93.5)
More often	15 (32.6)	7 (15.6)	3 (6.5)
Total	46 (100)	45 (100)	46 (100)
Non-responders	7	8	7
<i>Q15: I am satisfied with the sex I get from my steady partner</i>			
Less often	8 (19.5)	15 (38.5)	16 (39.0)
More often	33 (80.5)	24 (61.5)	25 (61.0)
Total	41 (100)	39 (100)	41 (100)
Non-responders	12	14	12
<i>Q20: I prefer masturbation</i>			
Less often	35 (81.4)	30 (71.4)	32 (74.4)
More often	8 (18.6)	12 (28.6)	11 (25.6)
Total	43 (100)	42 (100)	43 (100)
Non-responders	10	11	10
<i>Q21: I prefer not to have sex</i>			
Less often	43 (97.7)	35 (81.4)	35 (79.6)
More often	1 (2.3)	8 (18.6)	9 (20.4)
Total	44 (100)	43 (100)	44 (100)
Non-responders	9	10	9
All responses			
Less often	157 (50.5)	184 (60.1)	206 (66.0)
More often	154 (49.5)	122 (39.9)	106 (34.0)
Total	311 (100)	306 (100)	312 (100)
Non-responders	60	65	59
P value relative to "Before"		< 0.001*	< 0.001*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Table 5.5. This domain relates to issues that contribute towards participant's general drive and enjoyment. The collective statistics for these questions

show a statically extremely significant decline in this parameter at both investigated time points. This decline does not recover in the present (2002)

Table 5.6: Domain 5 : Drive and enjoyment – KAP Questions

Number (%) of participants				Non-responders
Agree	Disagree	Do not know	Total	
Q31: Condoms reduce pleasure				
22 (43.1)	27 (53.0)	2 (3.9)	51 (100)	2
Q32: Using a condom is unromantic				
15 (28.8)	34 (65.4)	3 (5.8)	52 (100)	1
Q44: I am too ashamed of HIV to use a condom				
3 (5.8)	47 (90.4)	2 (3.8)	52 (100)	1
All responses (n=155)				
All PH answers: 108 (69.7%)				

Table 5.6 Collective results from the KAP section of the questionnaire shows that current (in 2002) attitudes to condom use are mostly acceptable for public health interventions. Almost 30 % of respondents showed attitudes that might negate the use of condoms.

Table 5.7 : Domain 6 : Issues of anger and revenge

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>Q8: I use condoms with my steady partner</i>			
Less often	32 (72.7)	16 (38.1)	11 (25.6)
More often	12 (27.3)	26 (61.9)	32 (74.4)
Total	44 (100)	42 (100)	43 (100)
Non-responders	9	11	10
<i>Q14: I use condoms with my casual partner</i>			
Less often	22 (55.0)	8 (20.0)	6 (14.6)
More often	18 (45.0)	32 (80.0)	35 (85.4)
Total	40 (100)	40 (100)	41 (100)
Non-responders	13	13	12
All responses			
Less often	54 (64.3)	24 (29.3)	17 (20.2)
More often	30 (35.7)	58 (70.7)	67 (79.8)
Total	84 (100)	82 (100)	84 (100)
Non-responders	22	24	22
P value relative to "Before"		< 0.001*	< 0.001*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Table 5.7 show an increase in condom use with casual and steady partners since a diagnosis of HIV. This change is statistically extremely significant both

at one year after HIV and in the present (2002). This is related to issues of anger and revenge as explained in the discussion section.

Table 5.8 : Domain 6 : Issues of anger and revenge KAP Questions

Number (%) of participants				Non-responders
Agree	Disagree	Do not know	Total	
Q33: I use condoms only with my casual partners				
9 (18.7)	37 (77.1)	2 (4.2)	48 (100)	5
Q35: When I drink alcohol I don't think about condoms				
13 (26.0)	35 (70.0)	2 (4.0)	50 (100)	3
Q40: My partner must be faithful to me				
48 (92.3)	4 (7.7)	-	52 (100)	1
Q41: It's my job to protect my partner from HIV				
49 (94.2)	3 (5.8)	-	52 (100)	1
Q47: I don't care if I give HIV to my life partner				
-	48 (92.3)	3 (5.7)	51 (100)	1
Q53: Sex without a condom is a criminal offence				
19 (36.5)	25 (48.1)	8 (15.4)	52 (100)	1
Q54: I must be faithful to my partner				
46 (90.2)	4 (7.8)	1 (2.0)	51 (100)	2
All responses (n=356)				
All PH answers: 288 (80.9%)				

Table 5.8 Shows the KAP questions that relate to anger and revenge. These are further explored in the discussion section. It is important to notice that 80.9 % of respondents gave the PH answers for this domain

Note: PH answers were investigator defined as those answers given by participants which comply with social norms or which are conducive to the attainment of public health goals.

Table 5.9 : Domain 7: Accessibility to sex

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>Q5: How frequently do you have sex with steady partner</i>			
Less often	14 (33.3)	23 (54.8)	26 (60.5)
More often	28 (66.7)	19 (45.2)	17 (39.5)
Total	42 (100)	42 (100)	43 (100)
Non-responders	11	11	10
<i>Q6: How frequently do you have sex with casual partner</i>			
Less often	32 (74.4)	36 (83.7)	40 (90.9)
More often	11 (25.6)	7 (16.3)	4 (9.1)
Total	43 (100)	43 (100)	44 (100)
Non-responders	10	10	9
<i>Q7: How frequently do you have sex with anonymous partner</i>			
Less often	36 (83.7)	40 (93.0)	42 (95.4)
More often	7 (16.3)	3 (7.0)	2 (4.6)
Total	43 (100)	43 (100)	44 (100)
Non-responders	10	10	9
<i>Q11: How frequently do you have safe sex</i>			
Less often	26 (60.5)	15 (34.9)	9 (20.4)
More often	17 (39.5)	28 (65.1)	35 (79.6)
Total	43 (100)	43 (100)	44 (100)
Non-responders	10	10	9
<i>Q16: I prefer sex with casual partners</i>			
Less often	27 (64.3)	36 (87.8)	37 (88.1)
More often	15 (35.7)	5 (12.2)	5 (11.9)
Total	42 (100)	41 (100)	42 (100)
Non-responders	11	12	11
All responses			
Less often	135 (63.4)	150 (70.8)	154 (71.0)
More often	78 (36.6)	62 (29.2)	63 (29.0)
Total	213 (100)	212 (100)	217 (100)
Non-responders	52	53	48
P value relative to "Before"		0.063	0.053

No statistically significant changes from "Before" were found in the "Less often" / "More often" percentages (McNemar test)

Table 5.9 shows no statistically significant changes in the participant's accessibility to sex after a diagnosis of HIV infection at either of the studied time points.

Table 5.10 : Domain 8: Knowledge of safer sex

Number (%) of participants				Non-responders
Agree	Disagree	Do not know	Total	
Q23: <i>Kissing is safe sex</i>				
39 (76.5)	9 (17.6)	3 (5.9)	51 (100)	1
Q39: <i>My society will discriminate against me if they know I am HIV</i>				
28 (53.8)	18 (34.6)	6 (11.6)	52 (100)	1
Q42: <i>Oral sex (mouth to vagina) is safe sex</i>				
10 (19.6)	27 (52.9)	14 (27.5)	51 (100)	2
Q43: <i>Oral sex (mouth to penis) is not safe sex</i>				
25 (49.0)	16 (31.4)	10 (19.6)	51 (100)	2
Q49: <i>With a condom any lubricant is ok</i>				
10 (20.4)	29 (59.2)	10 (20.4)	49 (100)	4
Q52: <i>I have been counselled about safe sex</i>				
36 (69.2)	14 (26.9)	2 (3.9)	52 (100)	1
Q53: <i>Sex without a condom is a criminal offence</i>				
19 (36.5)	25 (48.1)	8 (15.4)	52 (100)	1
Q55: <i>Sex with dry vagina is safe sex</i>				
5 (10.0)	32 (64.0)	13 (26.0)	50 (100)	3
All responses (n=408)				
All PH answers: 231 (56.6%)				

Table 5.10 shows KAP responses to questions about safer sex. Boxed responses are the PH responses and were supplied by 56.6% of respondents.

Table 5.11 : Domain 9: Negotiation skills

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>Q4: Can you freely express your sexual desires</i>			
Less often	13 (28.3)	25 (54.4)	22 (47.8)
More often	33 (71.7)	21 (45.6)	24 (52.2)
Total	46 (100)	46 (100)	46 (100)
Non-responders	7	7	7
<i>Q10: I am comfortable suggesting a condom before sex</i>			
Less often	25 (54.3)	12 (27.3)	7 (15.6)
More often	21 (45.7)	32 (72.7)	38 (84.4)
Total	46 (100)	44 (100)	45 (100)
Non-responders	7	9	8
<i>Q13: I find it difficult to tell my partner what I want out of sex</i>			
Less often	33 (73.3)	34 (77.3)	29 (64.4)
More often	12 (26.7)	10 (22.7)	16 (35.6)
Total	45 (100)	44 (100)	45 (100)
Non-responders	8	9	8
All responses			
Less often	71 (51.8)	71 (53.0)	58 (42.6)
More often	66 (48.2)	63 (47.0)	78 (57.4)
Total	137 (100)	134 (100)	136 (100)
Non-responders	22	25	23
P value relative to "Before"		0.862	0.077

No statistically significant changes from "Before" were found in the "Less often" / "More often" percentages (McNemar test)

Table 5.11 shows an increasing ability of participants to negotiate their sexual needs with their partners at the present (2002) time point. This trend does not reach statistical significance.

Table 5.12 : Domain 9: Negotiation skills KAP questions.

Number (%) of participants				Non-responders
Agree	Disagree	Do not know	Total	
Q27: If I use a condom my partner will know I'm positive				
5 (9.6)	44 (84.6)	3 (5.8)	52 (100)	1
Q37: I don't know how to talk to my partner about condoms				
3 (5.8)	46 (88.4)	3 (5.8)	52 (100)	1
Q50: I discuss condoms with my partner before sex				
39 (78.0)	8 (16.0)	3 (6.0)	50 (100)	3
All responses (n= 154)				
All PH answers: 129 (83.8%)				

Table 5.12 Shows results from the KAP section of the questionnaire for the domain and 83.8% of respondents supplied PH responses

Table 5.13 : Domain 10 Social Functioning.

Number (%) of participants				Non-responders
Agree	Disagree	Do not know	Total	
Q22: If I don't have children my family will repudiate me				
10 (20.0)	34 (68.0)	6 (12.0)	50 (100)	3
Q24: I am not the man I used to be				
27 (51.9)	21 (40.4)	4 (7.7)	52 (100)	1
Q26: HIV has made me loose my status in my community				
10 (19.6)	37 (72.6)	4 (7.8)	51 (100)	2
Q29: If I use a condom, people will gossip				
5 (9.8)	44 (86.3)	2 (3.9)	51 (100)	2
Q30: If I use a condom there will be a fight with my partner				
1 (1.9)	49 (94.2)	2 (3.9)	52 (100)	1
Q36: My normal partner will think I am unfaithful if I use a condom				
8 (15.4)	42 (80.7)	2 (3.9)	52 (100)	1
Q39: My society will discriminate against me if they know I am HIV				
28 (53.8)	18 (34.6)	6 (11.6)	52 (100)	1
Q45: It's not in my culture to use a condom				
6 (12.0)	43 (86.0)	1 (2.0)	50 (100)	3
Q46: I am often sad				
26 (50.0)	24 (46.1)	2 (3.9)	52 (100)	1
Q51: I have told my children that I am HIV positive				
10 (22.2)	19 (42.2)	16 (35.6)	45 (100)	5
Q54: I must be faithful to my partner				
46 (90.2)	4 (7.8)	1 (2.0)	51 (100)	2
All responses (n= 558)				
All PH answers: 368 (65.9%)				

Table 5.13 shows KAP responses to questions that impact on social functioning and 65.9% of respondents supplied PH answers to these questions.

5.5 Cross tabular statistics

Domain data was analysed against demographic data of age, mode of transmission and ethnicity. Age was divided into two separate groups of below or equal to 35 years and above 35 years of age. This cut-off was decided based on the median age of participants, which was 37 years of age. Mode of transmission was divided into male-to-male and female-to-male. The results are reported below

Table 5.14 : Domain 4: Self-esteem and identity by age

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: Patients ≤ 35 years</i>			
Less often	9 (50.0)	10 (55.6)	12 (66.7)
More often	9 (50.0)	8 (44.4)	6 (33.3)
Total	18 (100)	18 (100)	18 (100)
Non-responders	2	2	2
P value relative to "Before"		0.564	0.046*
<i>All responses: Patients > 35 years</i>			
Less often	6 (25.0)	10 (41.7)	14 (58.3)
More often	18 (75.0)	14 (58.3)	10 (41.7)
Total	24 (100)	24 (100)	24 (100)
Non-responders	5	5	5
P value relative to "Before"		0.103	0.005*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Table 5.14 shows a decline in self-esteem and identity over time in both the under 35 and the over 35 age groups. These changes reached statistical significance in both age groups at the time point present (2002).

Table 5.15 : Domain 4: Self-esteem and identity by mode of transmission

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: Male-to-male patients</i>			
Less often	7 (36.8)	9 (47.4)	10 (55.6)
More often	12 (63.2)	10 (52.6)	8 (44.4)
Total	19 (100)	19 (100)	18 (100)
Non-responders	-	-	1
P value relative to "Before"		0.317	0.046*
<i>All responses: Female-to-male patients</i>			
Less often	5 (33.3)	6 (40.0)	11 (68.7)
More often	10 (66.7)	9 (60.0)	5 (31.3)
Total	15 (100)	15 (100)	16 (100)
Non-responders	4	4	3
P value relative to "Before"		0.564	0.014*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Table 5.15 shows a decline in self-esteem and identify over time in both the male-to-male and female-to-male modes of transmission. These changes reached statistical significance in the present (2002) time point.

Table 5.16: Domain 4: Self-esteem and identity by ethnicity

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: African patients</i>			
Less often	9 (36.0)	11 (44.0)	16 (61.5)
More often	16 (64.0)	14 (56.0)	10 (38.5)
Total	25 (100)	25 (100)	26 (100)
Non-responders	7	7	6
P value relative to "Before"		0.414	0.008*
<i>All responses: Caucasian patients</i>			
Less often	7 (41.2)	8 (47.1)	10 (62.5)
More often	10 (58.8)	9 (52.9)	6 (37.5)
Total	17 (100)	17 (100)	16 (100)
Non-responders	-	-	1
P value relative to "Before"		0.564	0.046*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Table 5.16 shows a decline in self-esteem and identity in both African and Caucasian patients over the time points. This trend reaches statistical significance in both groups in the present [2002] time point.

Table 5.17: Domain 5: Issues of drive and enjoyment by age

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: Patients ≤ 35 years</i>			
Less often	62 (51.2)	77 (63.6)	90 (71.4)
More often	59 (48.8)	44 (36.4)	36 (28.6)
Total	121 (100)	121 (100)	126 (100)
Non-responders	19	19	14
P value relative to "Before"		0.011*	<0.001*
<i>All responses: Patients > 35 years</i>			
Less often	85 (50.3)	96 (58.4)	102 (61.8)
More often	84 (49.7)	68 (41.5)	63 (38.2)
Total	169 (100)	164 (100)	165 (100)
Non-responders	34	39	38
P value relative to "Before"		0.014*	0.003*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Table 5.17 Demonstrates Issues of drive and enjoyment that were collectively analysed against the age of participants. Age of participants was divided into below or equal to the age of 35 and above the age of 35 as before. Results show a statistically significant downward trend in both age groups at all time points, but only reach extremely statistical significance in the present [2002] category in the age group less than or equal to 35.

Table 5.18 : Domain 5: Issues of drive and enjoyment by mode of transmission

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: Male-to-male patients</i>			
Less often	68 (53.1)	77 (62.6)	82 (67.2)
More often	60 (46.9)	46 (37.4)	40 (32.8)
Total	128 (100)	123 (100)	122 (100)
Non-responders	5	10	11
P value relative to "Before"		0.024*	0.001*
<i>All responses: Female-to-male patients</i>			
Less often	47 (46.1)	62 (60.8)	73 (67.0)
More often	55 (53.9)	40 (39.2)	36 (33.0)
Total	102 (100)	102 (100)	109 (100)
Non-responders	31	31	24
P value relative to "Before"		0.004*	<0.001*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

In Table 5.18 drive and enjoyment was analysed against mode of transmission. There is a statistically significant decline in drive and enjoyment from base line to the 1 year after HIV time point. This change is statistically extremely significant in the time point present [2002]' in both modes of transmission.

Table 5.19 : Domain 5: Issues of drive and enjoyment by ethnicity.

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: African patients</i>			
Less often	85 (48.3)	104 (59.1)	120 (65.6)
More often	91 (51.7)	72 (40.9)	63 (34.4)
Total	176 (100)	176 (100)	183 (100)
Non-responders	48	48	41
P value relative to "Before"		0.005*	<0.001*
<i>All responses: Caucasian patients</i>			
Less often	61 (53.0)	65 (59.1)	70 (64.2)
More often	54 (47.0)	45 (40.9)	39 (35.8)
Total	115 (100)	110 (100)	109 (100)
Non-responders	4	9	10
P value relative to "Before"		0.117	0.011*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

In Table 5.19, Drive and enjoyment was analysed against ethnicity. In the African patients, a decline in drive and enjoyment is statistically significant at the time point one year and extremely significant at the Present (2002) time point from baseline. The Caucasian group shows a statistically significant decline in the Present (2002) time point.

Table 5.20 : Domain 6: Issues of anger and revenge by Age

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: Patients ≤ 35 years</i>			
Less often	20 (62.5)	6 (19.3)	5 (15.1)
More often	12 (37.5)	25 (80.7)	28 (84.9)
Total	32 (100)	31 (100)	33 (100)
Non-responders	8	9	7
P value relative to "Before"		<0.001*	<0.001*
<i>All responses: Patients > 35 years</i>			
Less often	30 (63.8)	16 (34.8)	11 (23.9)
More often	17 (36.2)	30 (65.2)	35 (76.1)
Total	47 (100)	46 (100)	46 (100)
Non-responders	11	12	12
P value relative to "Before"		<0.001*	<0.001*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

In Table 5.20, issues of anger and revenge (defined as wilful transmission of the virus to another party and indirectly assessed by a reduction in safer sex practices over time) were assessed by age of participants. The categories less often and more often are pooled categories and pertain to safer sex practices. The results show a statistically extremely significant increase in the more often (safer sex) category in both age groups evaluated.

Table 5.21 : Domain 6: Issues of anger and revenge by mode of transmission

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: Male-to-male patients</i>			
Less often	22 (62.9)	12 (36.4)	8 (24.2)
More often	13 (37.1)	21 (63.6)	25 (75.8)
Total	35 (100)	33 (100)	33 (100)
Non-responders	3	5	5
P value relative to "Before"		0.007*	<0.001*
<i>All responses: Female-to-male patients</i>			
Less often	22 (73.3)	8 (26.7)	6 (18.7)
More often	8 (26.7)	22 (73.3)	26 (81.3)
Total	30 (100)	30 (100)	32 (100)
Non-responders	8	8	6
P value relative to "Before"		<0.001*	<0.001*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Table 5.21 describes issues of anger and revenge by mode of transmission and reveals a statistically extremely significant decline in unsafe sex practices in both male-to-male and female-to-male mode of transmission in the Present (2002) category.

Table 5.22 : Domain 6: Issues of anger and revenge by ethnicity

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: African patients</i>			
Less often	33 (70.2)	10 (21.7)	7 (14.6)
More often	14 (29.8)	36 (78.3)	41 (85.4)
Total	47 (100)	46 (100)	48 (100)
Non-responders	17	18	16
P value relative to "Before"		<0.001*	<0.001*
<i>All responses: Caucasian patients</i>			
Less often	16 (50.0)	12 (38.7)	9 (29.0)
More often	16 (50.0)	19 (61.3)	22 (71.0)
Total	32 (100)	31 (100)	31 (100)
Non-responders	2	3	3
P value relative to "Before"		0.102	0.020*

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

In Table 5.22 Issues of anger and revenge were evaluated by ethnicity. The categories less often and more often pertain to safer sex practices with a reduction in the less often category and an increase in the more often category collectively indicating an increase in safer sex practices. This decline in unsafe sexual practices reaches statistical significance in both groups but is extremely statistically significant in the Present (2002) time point in African patients.

Table 5.23 : Domain 7: Accessibility to sex by age

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: Patients ≤ 35 years</i>			
Less often	52 (62.6)	58 (69.9)	67 (76.1)
More often	31 (37.4)	25 (30.1)	21 (23.9)
Total	83 (100)	83 (100)	88 (100)
Non-responders	17	17	12
P value relative to "Before"		0.289	0.040*
<i>All responses: Patients > 35 years</i>			
Less often	72 (62.1)	82 (71.3)	77 (67.0)
More often	44 (37.9)	33 (28.7)	38 (33.0)
Total	116 (100)	115 (100)	115 (100)
Non-responders	29	30	30
P value relative to "Before"		0.077	0.354

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Table 5.23 shows a decline in accessibility to sex in the 35 and under age group, with an increase in those who responded less often and a decrease in those who responded more often. This decline in accessibility to sex is statistically significant at the present [2002] time point. In the age group over

35 years of age there was no significant difference to accessibility to sex before a diagnosis of HIV or in the present [2002] time points.

Table 5.24 : Domain 7: Accessibility to sex by mode of transmission

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: Male-to-male patients</i>			
Less often	57 (64.0)	63 (71.6)	60 (68.2)
More often	32 (36.0)	25 (28.4)	28 (31.8)
Total	89 (100)	88 (100)	88 (100)
Non-responders	6	7	7
P value relative to "Before"		0.273	0.516
<i>All responses: Female-to-male patients</i>			
Less often	46 (63.0)	50 (68.5)	57 (73.1)
More often	27 (37.0)	23 (31.5)	21 (26.9)
Total	73 (100)	73 (100)	78 (100)
Non-responders	22	22	17
P value relative to "Before"		0.433	0.144

No statistically significant changes from "Before" were found in the "Less often" / "More often" percentages (McNemar test)

Table 5.24 shows participants' accessibility to sex compared to mode of transmission. There is no difference in male-to-male mode of transmission or female-to-male mode of transmission at any of the time points.

Table 5.25 : Domain 7: Accessibility to sex by ethnicity

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: African patients</i>			
Less often	73 (61.3)	87 (73.1)	92 (74.2)
More often	46 (38.7)	32 (26.9)	32 (25.8)
Total	119 (100)	119 (100)	124 (100)
Non-responders	41	41	36
P value relative to "Before"		0.023*	0.011*
<i>All responses: Caucasian patients</i>			
Less often	52 (65.8)	55 (70.5)	54 (69.2)
More often	27 (34.2)	23 (29.5)	24 (30.8)
Total	79 (100)	78 (100)	78 (100)
Non-responders	6	7	7
P value relative to "Before"		0.439	0.548

* Statistically significant change from "Before" in "Less often" / "More often" percentages (McNemar test)

Table 5.25 shows a statistically significant decline in accessibility to sex, over all time points in the African group of patients. There is a marginal downward trend in this parameter in Caucasian patients.

Table 5.26 : Domain 8: Knowledge of safer sex by age

Age ≤ 35 years: All responses (n=158)
All PH answers: 94 (59.5%)
Age > 35 years: All responses (n=222)
All PH answers: 122 (55.0%)

Table 5.26 Shows knowledge of safer sex by age, and is divided into age groups less than or equal to 35 and above 35 years of age. Both age groups provided marginally more than 50% correct answers. The totals are lower than expected.

Table 5.27 : Domain 8: Knowledge of safer sex by mode of transmission

Male-to-male: All responses (n=150)
All PH Answers: 101 (67.3%)
Female-to-male: All responses (n=150)
All PH answers: 72 (48.0%)

Table 5.27 shows knowledge of safe sex by mode of transmission. The male-to-male mode of transmission group provided significantly more correct answers (67.3%) than the female-to-male group (48%). The female-to-male group provided less than 50% correct answers.

Table 5.28 : Domain 8: Knowledge of safer sex by ethnicity

African: All responses (n=244)
All PH answers: 127 (52.0%)
Caucasian: All responses (n=134)
All PH answers: 69 (51.5%)

Table 5.28 shows knowledge of safer sex by ethnicity, there is no difference between African patients and Caucasian patients.

Table 5.29: Domain 9: Negotiation skills by age

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: Patients ≤ 35 years</i>			
Less often	28 (51.8)	28 (51.8)	26 (46.4)
More often	26 (48.2)	26 (48.2)	30 (53.6)
Total	54 (100)	54 (100)	56 (100)
Non-responders	6	6	4
P value relative to "Before"		1.000	0.655
<i>All responses: Patients > 35 years</i>			
Less often	41 (54.7)	41 (56.9)	31 (43.1)
More often	34 (45.3)	31 (43.1)	41 (56.9)
Total	75 (100)	72 (100)	72 (100)
Non-responders	12	15	15
P value relative to "Before"		0.796	0.072

No statistically significant changes from "Before" were found in the "Less often" / "More often" percentages (McNemar test)

Table 5.29 shows negotiation skills by age groups, and shows no significant statistical differences between patients of 35 years or younger and those over 35 years at any of the measured time points.

Table 5.30: Domain 9: Negotiation skills by mode of transmission

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: Male-to-male patients</i>			
Less often	32 (56.1)	32 (59.3)	24 (45.3)
More often	25 (43.9)	22 (40.7)	29 (54.7)
Total	57 (100)	54 (100)	53 (100)
Non-responders	-	3	4
P value relative to "Before"		0.796	0.201
<i>All responses: Female-to-male patients</i>			
Less often	23 (52.3)	20 (45.4)	20 (42.6)
More often	21 (47.7)	24 (54.6)	27 (57.4)
Total	44 (100)	44 (100)	47 (100)
Non-responders	13	13	10
P value relative to "Before"		0.405	0.317

No statistically significant changes from "Before" were found in the "Less often" / "More often" percentages (McNemar test)

Table 5.30 shows negotiation skills by mode of transmission, there are no differences between male-to-male mode of transmission and female-to-male mode of transmission over any of the studied time points.

Table 5.31: Domain 9: Negotiation skills by ethnicity

Response	Number (%) of participants		
	Before HIV	1 year After HIV	Present 2002
<i>All responses: African patients</i>			
Less often	37 (48.0)	38 (49.3)	33 (41.2)
More often	40 (52.0)	39 (50.7)	47 (58.8)
Total	77 (100)	77 (100)	80 (100)
Non-responders	19	19	16
P value relative to "Before"		0.827	0.336
<i>All responses: Caucasian patients</i>			
Less often	30 (58.8)	28 (58.3)	21 (44.7)
More often	21 (41.2)	20 (41.7)	26 (55.3)
Total	51 (100)	48 (100)	47 (100)
Non-responders	-	3	4
P value relative to "Before"		0.739	0.071

No statistically significant changes from "Before" were found in the "Less often" / "More often" percentages (McNemar test)

Table 5.31 shows negotiation skills by ethnicity group. There are no differences between Caucasian and African patients at any of the studied time points.

Table 5.32 : Domain 10: Social functioning by age

Age ≤ 35 years: All responses (n=215)
All PH answers: 153 (71.2%)
Age > 35 years: All responses (n=304)
All PH answers: 184 (60.5%)

Table 5.32 shows social functioning stratified by age. There is a trend for participants of 35 years or less to have better social functioning as evidenced by 71.2% of respondents providing PH answers (*Vide Infra*)

Table 5.33: Domain 10: Social functioning by mode of transmission

Male-to-male: All responses (n=208)
All PH answers: 139 (66.8%)
Female-to-male: All responses (n=203)
All PH answers: 128 (63.1%)

Table 5.33 shows social functioning by mode of transmission. There is no difference in social functioning between the male-to-male and the female-to-male modes of transmission.

Table 5.34: Domain 10: Social functioning by ethnicity

African: All responses (n=336)
All PH answers: 220 (65.5%)
Caucasian: All responses (n=184)
All PH answers: 118 (64.1%)

Table 5.34 shows social functioning by ethnicity. There is no difference between the responses from Caucasians and African patients.

Chapter 6 Discussion

6.1 *Introduction*

The study was designed to evaluate the psychosexual functioning of a group of HIV positive men by assessing their knowledge attitudes, perceptions and practices in 2002 as well as evaluating (subjectively) the changes in their sexual functioning one-year after HIV infection, and the Present (2002) when compared to their pre-HIV diagnosis by means of a retrospective self reported questionnaire.

6.2 Partner profile.

Sex with sex workers is an often-quoted method of HIV transmission in South Africa; with differing degrees of impact,^{65,66} the sex work trade being prevalent in areas where travellers (truckers) or large groups of men congregate (hostels, army, police, and mines).

The percentage of participants attributing their infection to sex workers was very low and this is corroborated in other parts of the survey, which indicated that in this group, few respondents had sex with commercial sex workers before the diagnosis of HIV infection.

While public health interventions are often focussed on sex workers, the studied group might have benefitted more from interventions aimed and normal and occasional partners as this was the primary source of infection for them.

6.3 Reason for testing.

When asked to disclose their reason for taking an HIV test, 33.96% reported that they wanted to know their status and an equal number 33.96% reported

that they were sick at the time of testing. There was no difference between ethnic groups.

The number of men being tested because of illness is consistent with the perception that men are slow to take up medical services and that they present for medical care only if absolutely necessary. Even with an established diagnosis of TB, there remains a resistance to HIV testing.⁶⁷ The almost equal number of respondents who admit to being tested because they wanted to know their status, may be reflective of a changing dynamic in society and an increasing acceptance that HIV is a real factor in everyday life

6.4 Counselling

The data shows a very low counselling incidence with 52% of respondents receiving no counselling at all and only 21% respondents receiving both pre and post-test counselling. 19% only being counselled after the test.

Counselling is still not widely implemented in medical practices, and where it is, it is often perfunctory (neither at the time of the survey 2002 or at time of writing). This could be due to time constraints or due to failure to appreciate the importance of the intervention, despite many best practice documents.

Pre and post-test counselling are widely accepted to play a determinant role in the prognosis of the disease in individuals. Pre test counselling is a first step in imparting HIV disease knowledge to the patient. Additionally a relationship is established between the patient, the health care provider and the healthcare system, which should be welcoming and understanding of the patient⁶⁸⁻⁷⁰.

The patient should emerge from such a process with a clear understanding of what the disease is expected to do to them, what management options are available, and what the prognosis is if interventions are implemented. The relationship between patient and healthcare provider should be one that

engenders not only a non-judgmental attitude, thus creating a welcoming space for the patient, but also one in which the patient has confidence in the system and in the competency of professionals within the system.^{71,72}

Without pre and post-test counselling these goals are very difficult to achieve.

6.5 Adjustment time

Following a diagnosis of HIV infection, a period of psychological turmoil ensues. Patients require time to adjust to the implications and requirements of their new health status. Adjustment time is defined as the time period between a diagnosis of HIV infection and the time of completing the study questionnaire. Adjustment time was on average eight years for Caucasian participants and four years for African participants. The data does not show clear differences in trends when analyzed by year of infection, suggesting that, in this population, four years after diagnosis may be sufficient to bring about the majority of changes from before an HIV diagnosis to the present(2002) that were measured by the survey. It would therefore be logical to ensure that whatever interventions are implement to assist patients to adjust to their new status, should be continued for up to four years after diagnosis.

6.6 Changes in Sexual Behaviour.

Data, in this study, shows a statistically significant increase in the reported less risky sexual behaviour and an equally significant decline in the reported risky sexual behaviour at all time points (tables 5.1 and 5.2). This represents a sustained change over time spanning an average of four years in African patients and eight years in Caucasian patients. Many researchers have reported on a reduction in risky behaviour following a diagnosis of HIV, in the short term^{55, 54,73} Few have reported long-term sustainability of such changes.⁵⁴ Most researchers indicate a need for ongoing sustained

counselling in their recommendations., in order to sustain the measured changes.⁷⁴

The changes in sexual behaviour that are required by public health interventions in order to curb the spread of HIV in communities are difficult to achieve, in particular the consistent use of condoms during coitus. Kalichman et al⁷⁵ reported in 2006 that unprotected sexual activity in seropositive individuals was directly related to treatment beliefs and in particular to beliefs about reduced infectivity due to a low viral load. They did not measure psychosocial parameters. The viral load parameters were not examined in the present research.

The concept of reduced infectivity due to a low viral load was developed, in the literature, after the present study was completed, however it is unlikely that this would be an operative factor in risky sexual activity in the South African context, even at present, as viral loads are not done routinely in State institutions and patients are therefore uninformed of its significance. Such a consideration would be mandatory if research were to be done in the South African private sector today.

Results show that change in sexual behaviour towards less sexual risk taking, does occur after a diagnosis of HIV infection, and is sustained over time. Despite this positive change being statistically highly significant in the results, there remains a group of participants where this change did not take place. In 38% of respondents still practice risky sexual behaviour in the Present (2002), although less often than before.

Some psychosocial aspects as well as knowledge of what constitutes safer sex, might positively or negatively impinge on these results. This study investigated and described some of them

6.7 Self-esteem and identity – Domain 4

Self-esteem, as the opinion one has of oneself, both in the positive and negative realms is a major determinant of actions⁷⁶. This study looked at determining the changes, if any, in the self-esteem of participants, as a correlate of sexual behaviour.

High self-esteem is postulated to induce less risky sexual behaviour (as one would place high value on one's own existence and minimise factors that tend to threaten it.) Low self-esteem is postulated to result in the opposite behaviour.

A statistically significant decline in self-image over time was seen in the study. Data suggests that the longer the time from diagnosis, the more significant this decline became. The KAP section of this domain (Table 5.4) reveals that although 71% of participants exhibited attitudes consistent with good self-image, 21.8% revealed the opposite. In particular, responses showed that 52% of respondent felt they were no longer the man they used to be -, thus their self- image had declined, while 52% admitted that they were often sad. These two factors (decline in self-esteem and feelings of sadness) can independently be associated with clinical depression, which in turn will have an effect on behaviour.

Moskowits in 2011⁷⁷ reported that men's self-esteem is directly associated with the propensity to disclose serostatus with prospective sexual partner, the higher the self-esteem the greater the propensity. No such correlation was found in HIV negative individuals in his study.

In the present study depression was not measured in any detail (simply the tendency to feel sad) much work has been done on depression and HIV and high correlates between depression and HIV infection have been found all over the world ⁷⁸. Depression has a direct effect on self- efficacy i.e. the belief that one is able to do or accomplish something.⁷⁹ .Low self-efficacy translates in reduced ability to change sexual behaviour.⁸⁰⁻⁸⁴

Self-esteem is a known operand of behaviour and life development. Both these factors are operands in the individual's prognosis of any chronic illness, including HIV. The will to live and the feeling of having value, will determine a patient's day to day activity. A positive outlook on life is, therefore, more likely to create the situation where the prognosis of HIV infection is better.

6.8 Drive and enjoyment. – Domain 5

Drive and enjoyment were superficially studied and included both sexual and non-sexual questions. This data (Table 5.5) shows a worsening in the parameters for drive and enjoyment over time. While this change is expected in the first year after diagnosis, the expectation that this improves with time is not confirmed by the data. Unexpectedly, the data shows a progressive decline in this function into 2002. At both measured time points, this decline is highly statistically significant

Drive and enjoyment are fundamental to factors in the quality of life of participants. This reduction in drive and enjoyment may be the result of underlying depression, stigma, or reduction in self-esteem, or, conversely, may be a contributor to depression and reduction in self-esteem.

The popular belief that that condoms reduce pleasure and are unromantic,^{85–88} is confirmed in the KAP section of the questionnaire.

6.9 Anger and Revenge. – Domain 6

Anger and revenge are sometimes quoted in the media as reasons for the spread of HIV infection. A commonly held belief is that men, once having acquired HIV infection and becoming aware of such infection, respond with anger and wish to take revenge on society by deliberately spreading HIV further by refusing to use condoms in sexual encounters^{89,90}. This attitude is often summarized in the statement: "If I must go I will take as many as I can

with me “Additionally there exists an urban Myth that HIV infected persons will purposefully inject others with HIV positive blood from a syringe in shopping centres and other public places.

It must be stated that there is a clear difference in intent between not disclosing HIV status and not using protection during intercourse, and wilfully avoiding the use of protection with the *intent* to infect the new partner. This intent is left to the courts to determine, the infection of the partner is brought about by sexual exposure (mostly) during unprotected intercourse.

Results from the present study show that that there is an increase in safer sex practices after a diagnosis of HIV infection, but that a proportion (roughly 20%) have not changed their behaviour.(Table 5.7). Results from the KAP section of Domain 6 (Table 5.8) clearly show that participants accepted the need, not only for fidelity, but also to protect their partners from HIV Infection (92.3% and 94.2% respectively). There appears to be a disconnect between these two results, making the results in the KAP section questionable. Participants may have provided the responses they thought the researcher wanted to hear due to Social Acceptability Bias ⁹¹. Patients may choose the acceptable socially constructed answer for a number of reasons, including avoiding embarrassment, to please the practitioner, or to obtain praise. These factors may have been operant *see section 4.7.1*. Social Acceptability Bias leads to over estimation of socially acceptable responses, thus, these results should be seen with caution.

In those participants who have not changed to safer sex behaviours, the data suggests that the reasons for not changing, lie elsewhere than the wilful intent to infect another person,

6.10 Accessibility to sex. – Domain 7

The collective data shows no statistically significant change in accessibility to sex at any of the time points examined, however, responses to individual questions show different trends.

Questions 5, 6 and 7 were the appropriate questions for measuring this parameter. While questions 6: (*How frequently do you have sex with casual partner?*) and 7: (*How frequently do you have sex with anonymous partner?*) measured the frequency of sexual activity with various potential partners, question 5: (*How frequently do you have sex with steady partner?*) is directly indicative of sexual activity with one's regular partner. All show a decline in sexual activity over time. Additionally there is an increase in safer sex behaviours with both long-term and shorter-term partners and a reduction in sex seeking behaviour with casual partners.

The decline in sexual activity over time may be interpreted as difficulty in establishing new permanent relationships or difficulty in maintaining established relationships. Patients, who are HIV positive and aware of the consequences of their condition, find it difficult to establish new relationships.⁹² Barriers to new relationships are the issue of having children in a relationship, when and how to disclose one's status^{93,94}, and the fear of infecting the partner.⁹⁵

This reduction in sexual activity, while good for prevention activities seems to come at a high cost to patients.

6.11 Knowledge of safe sex -Domain 8

Cumulative data on this domain shows that 56.6% of respondents correctly identified the correct answers. Therefore, a worrisome 43.4% of respondents exhibited less than acceptable knowledge of safer sex.

Knowledge of safer sex is a crucial element in any HIV intervention. Not only does it meet the patient's need to understand how he may be putting himself or his partner at further risk for transmitting the virus, but also meets the needs of the primary public health prevention imperative.

Given the nature of the group studied, the result is an unexpected low figure and is clinically significant. It is probably indicative of the level of safer sex education currently available to HIV positive men, which focuses on condom use and penetrative intercourse. It is clear, that even in this highly experienced population, attending a sex friendly practice, more could be done to equip patients with the required level of detail. While the degree of knowledge about safer sex practices does not seem to consistently translate into a reduction of risky behaviour ⁹⁶, as many other factors may inhibit the implementation of intentions, it remains a fundamental requirement in informed decision making and consenting.

When analysed by mode of transmission, the male-to-male group (M2M) performed 19.3% better than the female-to-male (F2M) route of transmission.

Educational interventions for HIV prevention in the MSM population were started in the 80's by NGO's in South Africa and later, in the 90's were strengthened by some state funded projects. In the late 90's, as the epidemic spread, the shift was made to target heterosexual population by government and MSM interventions were once again left to NGO's.

These prevention messages are strongly targeted to specific at-risk populations and people, who do not identify themselves with the targeted population, do not perceive the messages as pertinent to them. Thus messages aimed at the gay population are not likely to be received by the heterosexual population.

A disparity in the length of time that the two groups may have been exposed to safer sex messages may account for the disparity in results. An additional factor may be the endemic nature of safer sex messages within the gay

community, and the level of detail that is traditionally supplied with these interventions. While the study was done in 2002, at the height of the Mbeki HIV/AIDS denialism era, which caused great confusion within the populace and severely hampered HIV prevention efforts, it is unlikely that this would have impacted on participant's knowledge of safer sex procedures, as safer sex issues were never really part of the denialist debate.

6.12 Negotiating skills – Domain 9

Some elements of sexual negotiating skills were investigated in Domain 9. Data shows a trend towards improved negotiation skills over the evaluated time periods, this trend does not reach statistical significance. The implications are that even allowing for a long period of adjustment time, participants still found it difficult to negotiate with their sex partners in terms of their requirements for a sexual event. Thus, this factor negatively influences the overall ability of participants to change their sexual behaviour after a diagnosis of HIV infection. Evaluation of question 4: (*Can you freely express your sexual desires?*), which measures this parameter directly, shows a distinct decline over time in the respondent's ability to discuss their sexual needs.(Table 5.11

6.13 General Social functioning – Domain 10

Some parameters of Domain 10 were described in the KAP section of the questionnaire.

The majority of respondents exhibited acceptable social functioning, with 65.9% of respondents providing socially acceptable (PH) answers.

It is commonly accepted that men in South Africa are socially expected to sire children. This practice is commonly believed to be stronger in African communities. Results from this questionnaire indicate that over 68% did not think that if they sired no children, this was a problem within their culture, but significantly, 20% did think it was, with the rest undecided. Thus in some

communities this traditional belief still places additional pressure on the HIV positive patient. The results obtained in this study may be a reflection of some change taking place in society or may be as a result of the demographics of the studied group, which was multicultural and where almost half of the respondents had sex with men.

General social functioning has been described in HIV positive men in a number of settings with a variety of Quality of life standardised questionnaires including ACTG SF-21,⁹⁵ and HRQOL⁹⁷ (health-related quality of life). Safren⁹⁸ reported in a multinational assessment of participants on a clinical study, that social functioning was not related to country but only to gender, with men having greater impairments than women.

Cross tabular analysis of this domain against mode of transmission or ethnicity showed no difference between the groups, while age showed a trend towards better social functioning of the order of 11.2% in favour of the under 35 age group. This may be attributable to a higher resilience and adaptability to change in this age group.

6.14 Limitations of the study

6.14.1 Population selection

The selected population consisted of middle-class to upper middle class working males, and was not representative of males in the country. Given the heterogeneity of the South African male population, with respect to ethnicity, culture, religious belief, and social stratum, it was inevitable that the selected population in any private practice would be statistically skewed. The results are not universally applicable, due to the small number of participants, even within the middle and upper middle class of males, as the sample was not representative of all the social strata. A bigger sample size and a more socially representative sample would be required in order to make the outcomes generalisable to any extent.

6.14.2 Population Bias

The population selected from this practice consisted of highly experienced patients who had been exposed to best practice management of HIV disease. The self-administration of the questionnaire limited participation in the study to literate subjects. While the inclusion criteria did not specifically exclude illiterate patients, it was known from the population profile of the practice that all potential patients were sufficiently literate to self-administer the questionnaire.

All patients were on ARV treatment at the time and were well versed in the functioning of ART. Results were obtained in 2002 and may not be applicable in the present as perceptions about HIV disease may have changed since then. The availability of ART through state institutions has certainly brought about more familiarity with the disease in the general population. Results are not necessarily reflective of similar populations in other practices or settings.

6.14.3 Randomisation Process

Randomisation process of 1:3 that was empirically decided upon in the planning of the study, did not lead to the desired result, but contributed to the small number of patients enrolled in the study.

6.14.4 Analytical Limitations

The analysis of the data generated by the study was severely hampered by the small sample size and the heterogeneity of the studied population. Statistical significance was obtained by pooling results from individual questions into their respective domains. Questions were included in a domain

if they directly or indirectly informed a domain. No weighting was done on these parameters and all questions were assumed to contribute equally to the outcome.

Weighting of the results may have resulted in different outcomes.

6.14.5 Questionnaire design

The questionnaire was designed by the investigator as no validated questionnaires were found that measured the areas the researcher wanted to investigate. Attention was paid to Social Acceptability Bias and measures were introduced to partially counteract this phenomenon. However, the questionnaire should have been subjected to more rigorous questionnaire design, testing and validation before it was implemented in the research program.

Chapter 7 Conclusion

The mean time from diagnosis to entry into this research was eight years for Caucasians and approximately four years for African participants. Results show that a reported change in the sexual behaviour of males after a diagnosis of HIV seropositivity does occur and is sustained over four to eight years. This change is exemplified by a reduction in risky sexual practices and therefore a potential reduction in transmissibility of the virus.

This change, while required by public health interventions, amongst other considerations, is predicated on a number of psychosocial changes, and comes at a considerable cost to patients.

Respondents showed reduced self-esteem and identity, self image, drive and enjoyment, a decline in sexual activity, an increase in depression or feelings of being sad, with reduced social functioning (for almost one third of respondents.) On the positive side, participants exhibited improved negotiation skills with regard to sexual matters. Most of these factors impact negatively on the Quality Of Life of People Living with HIV.

The majority of the participants did not have a clear understanding of what safer sex procedures actually are. This inadequacy is possibly the result of insufficiently detailed information normally given to patients. The thrust of interventions is on abstinence and the reduction of sexual partners. While this may be a valuable interventional strategy, it is not sufficient to ensure that people are protected when they do have sex, which is inevitable. To this extent, failure to address this aspect directly negates any gains that may possibly be derived from the implementation of the first two strategies. This area requires an increase in interventions aimed at educating both the public and the medical profession.

Risky sexual behaviour change after an HIV counselling intervention in HIV negative individuals is typically reported to occur, but only sustained for short

periods, even after intense interventions. HIV positive individuals on the other hand are expected to initiate and sustain this behaviour change lifelong.

The required change in sexual behaviour in HIV negative individuals can be motivated by self-interest (survival benefit, avoidance of disease and increased potential for longevity), however these considerations, for many patients, lack immediacy and therefore are no more effective than campaigns aimed at reducing smoking or increasing exercise. Without short-term tangible reward, such interventions are of little long-term effect.

Given the paucity of self-benefit provided to the HIV positive individual by a shift in sexual practices to less risky sexual behaviour, the adoption of such a change can only be predicated on social altruism. The long-term maintenance of such change can be construed to be more challenging.

Public health interventions would do well to consider the cost of this change to individuals and provide support structures to enhance the Quality Of Life of infected individuals, and to facilitate the maintenance of this behaviour change.

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Appendices

Appendix 1: Questionnaire

HIV Sexuality Questionnaire Male

Page 1

Thank you for agreeing to take part in this research programme .In the pages that follow you will be asked certain questions. Please answer ALL questions. When you have completed the questionnaire place it in the questionnaire box. Thank you

Age Caucasian Mixed race African Asian

What year did you first test positive for HIV? Latest CD4 count Date?

Please indicated the way you acquired your HIV Infection

Sexual: Female-to-male Male-to-male Blood transfusion
Sexual Contact Type Sex with normal partner Sex with casual partner
Sex with commercial sex worker Don't know

Why were you tested for HIV? Please mark all that apply

I wanted to know My partner tested positive I was sick For insurance

Where were you first tested for HIV?

Government hospital District clinic? Private Doctor Laboratory

Did you receive counselling before and after your HIV Test?

Only Before the test Only after the test Before and after Had counselling no

The questions that follow are about your sexuality and your sex life. The questions are divided into the time before you became HIV positive, the first year after your HIV test and Now.

For each question write in a value from one to four (1-4)Where :1=Almost never , 2= Sometimes, 3=Most of the time 4= Almost always

		Before HIV Q	First year of HIV	Now
	Question			
1	Do you think you are sexually attractive			
2	Are you satisfied with your sex life			
3	Do you have a high sex drive			
4	Can you freely express your sexual desires			
5	How frequently do you have sex with <i>steady</i> partner			
6	How frequently do you have sex with <i>casual</i> partner			
7	How frequently do you have sex with anonymous partner			
8	I use condoms with my <i>Steady</i> partner			
9	I am a bad person			
10	I am comfortable suggesting a condom before sex			
11	How frequently do you have safe sex			
12	I use alcohol before sex			
13	I find it difficult to tell my partner what I want out of sex			
14	I use condoms with my <i>casual</i> partner			
15	I am satisfied with the sex I get from my <i>steady</i> partner			
16	I prefer sex with casual partners			
17	I prefer vaginal sex			
18	I prefer oral sex			
19	I prefer anal sex			
20	I prefer masturbation			
21	I prefer not to have sex			

HIV Sexuality Questionnaire Male

The following section please indicate if you agree or not with the question. The Don't know column may only be marked if it is white

	Questions	Agree	Don't agree	Don't know
22	If I don't have children my family will repudiate me			
23	Kissing is safe sex			
24	I am not the man I used to be			
26	HIV has made me loose my status in my community			
27	If I use a condom my partner will know I'm positive			
28	Don't need to use a condom- my partner is also positive			
29	If I use a condom, people will gossip			
30	If I use a condom there will be a fight with my partner			
31	Condoms reduce pleasure			
32	Using a condom is unromantic			
33	I use condoms only with casual partners			
34	Real men don't use condoms			
35	When I drink alcohol I don't think about condoms			
36	My normal partner will think I am unfaithful if I use a condom			
37	I don't know how to talk to my partner about condoms			
38	Vaginal penetration without a condom is safe sex			
39	My society will discriminate against me if they know I am HIV			
40	My partner must be faithful to me			
41	Its my job to protect my partner from HIV			
42	Oral sex (mouth to vagina) is safe sex			
43	Oral sex (mouth to penis) is not safe sex			
44	I am too ashamed of HIV to use a condom			
45	Its not in my culture to use a condom			
46	I am often sad			

47	I don't care if I give HIV to my life partner			
48	I must have children			
49	With a condom any lubricant is OK			
50	I discuss condoms with my partner before sex			
51	I have told my children that I am HIV positive			Not applicable
52	I have been counselled about safe sex			
53	Sex without a condom is a criminal offence			
54	I must be faithful to my partner			
55	Sex with dry vagina is safe sex			
56	Please describe other ways that HIV infection has changed the way you practice and enjoy your sex life:			

Appendix 2: Patient's Informed Consent Document

Informed consent document.

You may be eligible to participate in this new research program as has been discussed with you by your doctor.

Study title.

Psychosocial factors associated with sexual functioning in a group of HIV positive men

Eligibility for the study

You are eligible to participate in the study if you are 18 years or older, are male, HIV-positive, able to give consent, and have not participated in the study before.

Participation in the study, or refusal to participate, is entirely voluntary and will not compromise your ongoing care at the centre in any way.

There is no financial reward for participating in the study.

Study rationale:

As an HIV-positive man, you have often been told to practice safe sex. Unfortunately, the epidemic continues to grow unabated, and the perception exists that men do not want to use safe sex. Many studies have shown that only a small percentage of HIV positive men practice safe sex, and even those who do, eventually fail to do so consistently. Many of interventions designed to address this problem, have been punitive in nature. There is a need to look at what are the reasons why men do not practice safe sex, so

that these problems may be addressed in a way that makes sense to you, the person with HIV.

Objectives of the study.

The objectives of the study are to describe some of the issues mentioned above. This will be done by means of an anonymous questionnaire and your name will not appear anyway on the document. This is because your identity is not important, what is important is what **you** think and how **you** feel about certain things. For this reason, we would ask you to be very truthful in answering the questionnaire. If your answer is not the one that society would expect you to give, please give us your answer anyway, what we are really interested in is how you feel, not what society thinks you should feel. There are no right or wrong answers. When you read the question please mark the box, or enter the number that is closest to what you feel about that question. Further instructions will be given in the questionnaire.

Course of the study.

The study consists of you filling in a questionnaire, in the privacy of a separate room and putting into the appropriate box. The questionnaire is entirely anonymous and completion should not take longer than 10-15 minutes.

Possible risks to you.

Your participation in the research program may involve certain risks of which you should be aware. Some of the questions in the questionnaire may make you think about certain sexual practices, certain values, and certain areas of your life which you may not have thought of before, or which may be a problem to you. Thinking of these things may be painful and may make you feel upset or unhappy or confused. For this reason, if any of these things should happen, you will be offered the possibility of having a counselling session, either with Dr Baraldi, or with Mr Richard Seleck, our psychologist. A maximum of two free counselling sessions will be offered to assist you in

dealing with the issues raised. For this purpose, you will be supplied with two coupons, which you will need to hand in at reception when making an appointment for this.

Possible benefits to you:

Participation in the study has possible benefits to you. You will have a chance to explore issues related to your own sexuality and should find this a positive growth experience. Additionally at the end of the research, the study results will be made known to you. This is an opportunity to evaluate yourself against you peers.

Confidentiality:

Since the questionnaire is anonymous and your name does not appear on any of the documents, your confidentiality is guaranteed

Thank you for agreeing to take part in this project.

Dr. Ezio Baraldi

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